

PRESCHOOL BLIND CHILDREN
AND THEIR PARENTS
Lela B. Carr

HV/661
C



**M.C. MIGEL LIBRARY
AMERICAN PRINTING
HOUSE FOR THE BLIND**

47754-MIGEL

*Child welfare workers head up a statewide
program of services to . . .*

PRESCHOOL BLIND CHILDREN AND THEIR PARENTS

LELA B. CARR, M. A.

Assistant Superintendent, Division of Child Welfare, Illinois Department of Public Welfare

HOW CAN I teach my blind baby to eat solid foods? Will he be able to get through school? Will he have to associate only with other blind people? How can he make friends? How will he earn a living?

These and many other questions face the parents of blind children. And beneath them often lies the unasked, tormenting question: "What have I done to bring this about?"

Such questions spring normally from a parent's reaction to his child's blindness, but they call for expert help not only in making available more information about blindness, a blind child's needs, and ways of meeting them, but also in coping with the emotional problems that underlie and accompany them. The sooner such help is proffered to the mother and father of a blind child the more likely are they to be able to help their child develop to the fullest his capacities as a human being.

In Illinois a growing realization of this need has been behind the development of a comprehensive program for pre-school blind children and their parents in which the Department of Public Welfare plays a prominent role, along with a number of other agencies, both public and private.

The program got underway back in 1946. That year the department, through its division for the blind, initiated a demonstration project which provided a home counselor for parents of pre-school blind children in Chicago. Cooperating with the division in the establishment of the program were the department's division of child welfare, the Chicago Public Schools, the State Commission for

Handicapped Children, Illinois Public Aid Commission, the Division of Child Welfare, Chicago Council of Social Agencies, and the University of Chicago Eye Clinics. Some of the same agencies, and a few others, were also involved that same year in planning and conducting an institute for parents of pre-school blind children held at the State School for the Blind, the first one of a series of institutes which is still going on.

Simultaneously, the Department of Ophthalmology of the University of Chicago Clinics, with the cooperation of medical staff and the Departments of Psychology and Social Service of the Clinics, was engaged in a special project to study the problem of the adjustment of blind children and their families to permanent blindness. This project had been prompted by recognition of the increasing incidence of blindness in children caused by retrolental fibroplasia, an eye condition associated with prematurity the cause of which was not then known.¹

All the agencies cooperating in these programs have worked on the theory that a blind child should be given opportunities to live as normal a life as possible. Their joint objectives have been to locate preschool blind children and to make what services they need available on a statewide basis.

In 1949, the department's project advanced from a "demonstration" to a permanent program and, in accordance with the basic philosophy that blind children are first of all children with the same needs that other children have, was administratively transferred from the division for the blind to the division of child welfare, with child welfare workers carrying

responsibility for providing the counseling services in various parts of the State.

A 2-day institute was held at the time of transfer to provide child-welfare workers relevant information regarding blindness and blind children. Representatives of the agencies that had initiated the program discussed casework skills, the education and home training of the child, teaching parents how to do the training, and current knowledge on blindness and blind people and the problems of being blind.

Counseling Service

From the beginning the counseling experience has pointed up certain basic principles of the casework process: the importance of beginning with the parents where they are, in this instance in a state of fear, anxiety, and often defeatism; educating through the provision of information; helping through relationship; enlisting interest through interpretation; making use of available community resources.

As in all casework effort, the experience has met with varying degrees of progress in individual situations. There have been success stories, like the following:

Bobbie's parents could not accept their baby's blindness. Until he was two, they clung to the hope that his eye condition would improve. By that time, however, their anxiety was increasing because they realized that he was retarded in comparison with other children of his age. In spite of Bobbie's inability to do many things that would be expected normally of a 2-year-old, the counselor observed that he seemed to be intelligent and alert.

Although the mother had not given up hope that Bobbie would have some sight, she said she knew that she and the father could not wait until he could see to begin his training. She knew that they should have done more than they had. She asked what kind of toys should be provided for a blind child but seemed unconvinced when told there were no special toys needed and only a few toys had to be eliminated from his experience. The counselor spent some time in discussing the use of toys, pointing out that the blind child might need considerably more help than the sighted child in learning how to use them, and that this required some body manipulation by the parents. Bobbie's mother then asked about educational facilities, implying that she did not understand at all how a blind child could be educated. The counselor told her of the educational facilities which existed in the city and of the State residential school.

This mother had only vaguely heard about Braille and was thrilled when the counselor told her about it in detail. To give her a feeling of greater encouragement for the future the counselor told her about some educational devices, such as raised relief maps, Braille music, Braille typewriters, the use of regular standard typewriters and other educational means.

The counselor also pointed out that many children go to regular nursery school with sighted children when they are 3 years old or a little older, but the mother found considerable difficulty in accepting this possibility.

It was hard for this mother to let the interview end. She was most eager for a definite return appointment and since the counselor felt that this was an intelligent approach and that the mother seemed ready to use services, an appointment was given her for 2 weeks hence.

The counselor continued interviews with Bobbie's mother on a regular basis. During those the mother brought out more of her feelings of wanting to do everything she could for Bobbie but of deep disappointment in having a blind child and resentment over the extra responsibilities. The process of helping her reach the stage where she could give Bobbie more freedom to move about and explore, of helping her understand her hostility and the resultant guilt when she disciplined him, of encouraging her to take some time off from caring for Bobbie for herself, and of helping her gain an understanding of the uses she could make of the interview situation, involved skillful use of relationship and the authority of knowledge about the handicap of blindness.

Institutes for Parents

As a supplement to the counseling program and in line with the proposals in the cooperating agencies' statewide plan, the program has involved the development of annual summer institutes for the parents of pre-school blind children, held at the State School for the Blind, now called the Illinois Braille and Sight Saving School. These provide parents from all parts of the State with the opportunity not only to receive information on different aspects of child care and development, but also to participate in group discussions with others who are facing experiences and problems similar to their own.

Certain features have characterized the planning and conducting of the nine annual institutes which have thus far been held. An advisory and planning committee has enlisted the cooperation and support of a number of public and private organizations interested in services to parents and their blind children. These have shared a large degree of responsibility, in case finding, financial assistance, loan of specialized staff, or consultation service. Provision has been made for the attendance of children as well as parents. The institute program through 5 years has been organized to give information about many phases of child development and blindness, its medical, social, educational, and personal aspects. Increasing opportunity has been given parents to

tending the institute to have individual conferences with consultants, social workers, and teachers.

Each year the staff and planning committees have evaluated the institute, and parents have been asked to make suggestions for changes that would increase its value to them. These evaluations have resulted in changes in emphasis but the purposes have not changed since they were clearly and fully stated by the original planning group.

The experience of the first institute, held August 5-30, 1946, produced recommendations which have given direction to succeeding institutes ever since. This showed the need for more medical and social information for providing help to individual mothers; a comprehensive plan of orientation for all participating staff; staff meetings during the institute so that indicated changes in program could be made and emerging problems handled; more opportunities for the children to have outdoor play involving large muscle activities; a weekend session to provide fathers with an opportunity to attend at least part of the institute.

Fathers have attended in increasing numbers since the first institute, although some of them could be present only over the weekend. Other members of the family group, important to the child, have been invited in particular instances. They have included grandmothers, aunts, sighted siblings and foster parents. Parents whose children are too young to be brought along have also been encouraged to attend.

While the lecture method was employed in the beginning, in recent years the program has been developed around the workshop method with three or four groups of parents led by a child welfare worker or a nursery school teacher.

One significant value in having the children attend is the opportunity it gives parents to observe blind children other than their own and to see the reactions of the children to opportunities for achievement provided in an enriched nursery school program under the leadership of qualified professional staff. Some children walk alone for the first time; others hold their own glass of fruit juice; some ride a tricycle and dare to use the slide. Parents are usually able to allow their children more freedom after they return home. The institute's nursery school also helps parents and children to experience separation under desirable conditions, for many, their first separation. It also affords an excellent opportunity for staff to determine the child's stage of development and to evaluate his capacity to make progress, so that they



COMMUNITY, as well as parental, attitudes toward blindness are extremely important to a child's adjustment. The case-worker's skill in cultivating healthy community attitudes can help the blind child relate to normal society in a mature way.

can give help to the parents and whatever agencies are working with them.

A toy shop developed from ideas given by a consultant on toys at a general meeting has become an established part of the institute and attracts parents, staff, and visitors like a magnet. Many fathers and some mothers get pleasure out of operating the power machinery under the guidance and direction of the School's manual training teacher. They take pride in the chairs, tables, hobby-horses, building blocks, easels, wooden animals, and numerous other items they make.

The institute provides new and stimulating experiences for both parents and children. Last year, the pediatrician stayed with the group 2 hours after her formal talk to answer questions. The ophthalmologist had the same experience after explaining the structure and care of the eyes. Parents of even the youngest children want to know how their children can be educated and a special meeting is devoted to facilities and resources for education. Many apply themselves with great intensity to learn Braille. On one occasion, when a mother asked if she should



RELATIONSHIPS between parents and a blind child can be as healthy as those with a physically normal child, but blindness can impose a strain on both. The caseworker's skill in helping to strengthen these relationships is invaluable.

to teach Braille to her child, the teacher suggested that she "help him to be ready to learn Braille," by teaching him the meaning of "top" and "bottom" of a page—an essential concept in Braille, but extremely difficult for a blind child to grasp.

Informally, parents talk long hours with two consultants who are themselves blind. Parents want to know what it is like to be blind. Their questions relate to almost every aspect of living. They want to know what the future holds for their blind children. The approach used with them is that blindness, although a sensory limitation, does not prevent happy, useful living and attaining accomplishments that can be a source of gratification and pride.

Not the least of advantages for some parents, is the opportunity to have a vacation in an expanse of grass and trees, with excellent free meals, an hour each day in the swimming pool with their children, an evening of stunts and games or dancing, and time to sit on the lawn and visit.

Over the years, gains in knowledge and understanding, changes in program, and swelling at-

tendance have demanded steady increases in staff from various professional disciplines. The first institute was attended by 21 mothers and 20 children. The 1954 institute was attended by 32 parents with 15 out children and 24 parents with 15 children, the 50 parents present representing 36 blind children.

In 1946 the salary of the first home counselor was paid from private funds. Housing and board of staff, parents, and children were provided by the State School for the Blind at the first and all succeeding institutes. The staff was loaned by sponsoring agencies. Since 1950 additional staff, travel costs of staff to and from the institute, and materials have been provided through Federal Child Welfare Services funds and have amounted to approximately \$3,000 per year. These funds also cover the salaries of two child welfare workers in the Chicago area where the number of families receiving service warrants specialized caseloads. They also cover nursery school fees for children whose parents cannot pay tuition.

Use of Nursery Schools

Nursery schools that have been willing to admit a blind child to their groups of sighted children are making an inestimable contribution to the development of these children. Here is a teacher's story of what a nursery school did for Jimmy who feared new objects and all children.

It was my view that adults to him may have been strange wonderful beings who could do marvelous things that Jimmy could not do, and he was aware of his dependence on them for the things he could not do for himself. Moreover, they centered a great deal of attention on him, gave him undivided consideration, so that though he could not see them he could feel like a king with others bowing down to him, anxious to please him.

Children, however, were different to him. Not only could he not know how to respond to them but they represented a complete threat to his security. How is one to explain children who can see and do things that Jimmy cannot do? How is one to teach cooperation and living with others to a child who has no conception of others and is so completely self-centered that other children do not exist in his mind?

Jimmy's eagerness and his enthusiasm for nursery school were always encouraging signs. He soon outgrew the experience of going up and down the slide and was ready for new experience—the swings, the barrels, the chicken coop, and the walking boards. At the very beginning he would express a strong desire to go on the swing; after sitting down on the seat he would ask to be removed. There was no strong expression of fears; there was rather an expression of insecurity as if he did not know what to expect but would not wait to find out. From time to time I brought him back to the swings. Then after a week had passed, he finally consented to be pushed. For a moment he was frightened but as I

him, his fear changed to genuine enjoyment. I sang a song about a swing as I pushed him up into the air and for weeks afterwards he associated the swing with the song.

I attempted, too, to introduce Jimmy to some aspects of routine, but during the first month I made no attempt to have him become a part of the group. It was always difficult to keep him seated for any length of time. Because his interest span was limited I spent a tremendous amount of time trying to channelize his energy. Around and around the room he went, touching this thing and that, up the stairs and out of the door of the playroom leading to the staircase in the building. At first everyone expected Jimmy to have special privileges, especially since we were trying to cultivate his interests to a point where they would be more sustaining. However, as I became more familiar with his behavior I felt it would be necessary to have him become aware of the fact that there were children about him who were also interested in the things that appealed to him. Until we introduced the idea of sharing his toys or giving up the swing to another child he generally stayed out of the other children's way or would make sure that they were not in his way by pushing them aside quite vigorously.

As Jimmy persisted in his aggressive behavior, I told him that if he pushed the children he might get pushed back. At this particular time I felt that he was quite ready for this kind of control, that in order to learn his relationship to others about him, he must learn it in a perfectly normal fashion as

OME 5,800 children under 7 years of age, or 1 in every 4,000, is estimated, are blind. In the school-age group, the total some 6,600 or 1 in every 5,000. Many are in residential schools; only a few are in special public school classes.



any other child would learn. In no other way could he gauge the reactions of those about him. Moreover there was no other way through which he could establish his standards of value of what one can do and what one cannot do.

We decided, therefore, to treat Jimmy as we would any other child. However, we began this gradually so that his sense of frustration at the very beginning would not be too intense. Jimmy responded very well. He did not react strongly to waiting like the others for a turn on the swing or to giving up the bicycle after he had had it for quite a while, though like most of our sighted children he was impatient at first about having to wait his turn. Soon Jimmy was sent out on the playground with the other children and although he still received some individual attention he began to acquire a degree of independence.

Toilet routines particularly began to reveal Jimmy's increased confidence in being able to do things for himself. He loved to wash his hands and to splash about in the water. With encouragement he became able to pull up and adjust his clothing, though he showed some reticence at first, saying "I can't, you do it." When we could convince him that what we demanded of him was a relatively easy task, he found that he was able to accomplish the job.

Jimmy was able to manipulate the hot and cold water faucets within a short period of time and to reach around the basin to find the soap. He also took pride in finding his own paper towel. Often he would grope about the wall for some time but when I offered assistance he would refuse, saying he wanted to find it himself. He became able to locate the wastebasket and would drop his towel inside when he had finished drying his hands just as the other children did.

It is not possible to include all the exciting details of the process through which the teacher helped Jimmy learn to do things for himself. In her record she concluded:

Gradually, I found it necessary to spend less and less time with Jimmy. As he no longer needed my presence so greatly, I turned him over to the other teachers and the children in his group. By degrees he became increasingly independent and soon we found ourselves regarding him as any other child. He was able to manage himself as well as any child, running about, trying out the toys, going up to the slide and riding in the swing. It was not long before he was entering into all activities with the other children.

Jimmy's development is an illustration of the kind of contribution that a number of nursery schools are making in accepting a blind child with sighted children.

Parents' Groups

The participation of child welfare staff in parents' groups has varied in different sections of the State. The Parents of the Blind in Chicago, established several years ago, is an active, forward-looking group organized by the parents in an effort to help one an-

other. The group undertakes numerous projects including publication of a monthly, *The Outlook*, which provides the membership with information and the opportunity to exchange ideas. The parents assume leadership and responsibility although the child-welfare workers attend meetings as interested participants.

Another parents' group, in Peoria, operates a day camp during the summer and for the past 2 years has employed child-welfare workers, formerly on the State staff, as camp directors.

In the Carbondale area the department's child welfare staff took leadership in organizing and guiding a parents' group. While several meetings were held over the period of a year, attendance remained low because of travel difficulties, and the group eventually disbanded. Similarly a parents' group organized in East St. Louis under the joint sponsorship of the Family Service Association of Alton and the Department of Public Welfare regional office lapsed after a series of meetings in which the parents seemed to find a good deal of release in talking with each other about their difficulties. Just as parents become less dependent on individual counseling as they gain security, their need for institutes and parents' groups declines as their confidence grows.

The experience since 1946 has revealed four major facts about services to parents of preschool blind children: 1) These parents have real anxieties around the handicap of blindness, requiring special help; 2) effective methods of providing service include individual casework counseling and group counseling;

3) skilled workers are needed with special knowledge, understanding, and motivation, to carry on the services; 4) the achievement of objectives in providing service is also related to a service conviction.

The Department of Public Welfare still faces many problems in providing more effective service to the parents. The amount and quality of casework service given by the agency is not uniform throughout the State. While there seems to be an advantage in assigning all such cases within a given region to one worker because of the special knowledge about blindness the work requires, this practice is not realistic in rural areas where families live great distances apart. Outstanding work has been done occasionally by workers with only one or two preschool blind cases in a mixed caseload, but too often "case closed, family did not want service" has been the only result.

Actually, the agency has not succeeded with its staff in stimulating interest, concern, and a sense of responsibility for this service. Some workers, like the parents, regard blindness as something so very different that they do not know what to do. Despite these problems, the agency must continue to ask itself whether it is truly answering the parents' question: Can I or anyone else really teach my child? Can he lead a normal life? Why has this happened to my family? The challenge to the agency is to find answers and give the right and honest answers to each individual.

¹Norris, Miriam: Some Social Problems Presented by the Increasing Incidence of Blindness Among Children. Paper presented at Medical Women's Association Breakfast, Annual Meeting, Illinois State Medical Society, May 1949.

The personality of the child, in which memory plays so vital a part, requires protection even more than his physical health and mental development. It has become a trite saying that children need security. They need to have a sense of belonging—of being important to someone and of having a share in the things that pertain to their small world. It is not alone freedom from want that is implied, but security in the affection of those who are responsible for his upbringing, and protection of his rights as a personality. Perhaps another thought should be added to the expanding philosophy of the rights of children: childhood is important in itself; it is not only a period of preparation for life as an adult and as a citizen. Children as children have certain inalienable rights. . . .

EMMA OCTAVIA LUNDBERG, 1881-1955

"Unto the Least of These," D. Appleton-Century Co., 1947

HV1661

c. 4

C

Carr, B. Lela
Preschool blind children and their
parents.

Date Due

HV1661

c. 4

C

Carr, B. Lela

AUTHOR

Preschool blind children and their
parents.

TITLE

DATE
LOANED

BORROWER'S NAME

PAMPHLET BINDERS

This is No. 1527

also carried in stock in the following sizes

	HIGH	WIDE	THICKNESS		HIGH	WIDE	THICKNESS
1523	9 inches	7 inches	$\frac{1}{2}$ inch	1529	12 inches	10 inches	$\frac{1}{2}$ inch
1524	10 "	7 "	"	1530	12 "	9 $\frac{1}{8}$ "	"
1525	9 "	6 "	"	1932	13 "	10 "	"
1526	9 $\frac{3}{4}$ "	7 $\frac{1}{8}$ "	"	1933	14 "	11 "	"
1527	10 $\frac{1}{2}$ "	7 $\frac{3}{8}$ "	"	1934	16 "	12 "	"
1528	11 "	8 "	"				

Other sizes made to order.

MANUFACTURED BY
LIBRARY BUREAU
Division of REMINGTON RAND INC.
Library Supplies of all Kinds

